

Chicago Tribune, December 27, 2005

Illinois residents wondering if they have HIV, the virus that causes AIDS, may find themselves facing difficult decisions next month when the state begins tracking the virus using patients' names instead of anonymous codes.

People still will be able to get an anonymous HIV test with an assigned number through which the results are reported. But if someone who tests positive goes to a doctor or hospital for care, the provider will have to report the patient's name to local health authorities.

Public health officials insist that names will remain confidential, just like the identities of people with AIDS or other infectious diseases that are tracked by name already.

AIDS activists say they are resigned to the change because much-needed federal funds would be jeopardized without it. Yet advocates also fear that the move will deter some people from seeking treatment early, when it's most likely to help.

"Anonymity has always been part of successful testing programs," said Brad Ogilvie, who runs an AIDS prevention group in the western suburbs called the Mosaic Initiative. "My concern is we're never going to get those who most need to know their status if we tell them, 'By the way, if you're HIV-positive, your name goes in to the state.'"

Until now, Illinois has tracked HIV patients by unique alphanumeric codes, a strategy designed to encourage testing by protecting the identity of people who carry the virus.

But officials at the federal Centers for Disease Control and Prevention say code-based reporting is less accurate, so the agency counts only those HIV cases reported by name. Because CDC figures are used to divvy up federal funds, Illinois faced a loss of money if it didn't agree to change its method.

"The state is being forced to move to name-based reporting or risk losing millions of dollars for essential HIV care services," said David Munar, associate director of the AIDS Foundation of Chicago. "We'll look like we have no recorded cases of HIV diagnosed in Illinois because they won't accept our data, when we've actually collected more than 14,000 case reports since 1999."

The new policy was prompted by the expiration of the Ryan White CARE Act, the federal program that funds services for people living with AIDS and HIV. Congress is expected to make critical changes in the statute when lawmakers vote to reauthorize it next year.

If the Bush administration has its way, the new version of the law will shift millions of dollars away from urban centers such as Chicago to expand care in rural areas. In addition, the formula for distributing the money would be based on the number of HIV and AIDS cases in each area, instead of just the AIDS cases, as is the case now.

So unless Illinois and about a dozen other states conform to the CDC policy and stop tracking HIV by code, they will not obtain their full share of funding. Munar estimates that, under the administration's proposal, Illinois would lose at least 10 percent of the more than \$74 million per year it now gets from the CARE program, beginning in fiscal year 2007.

The proposed changes have activists and public health officials waging a battle on two fronts: to prevent the loss of funding and to preserve the trust of infected individuals.

"If there's anything that would motivate people not to get tested, it's the fear that the information will get out," said a Chicago-area professional who has been living with AIDS for more than two decades. "People don't go in to get tested. So, what do they do? They infect somebody else."

The man, who asked that his name not be printed, said he would never have been tested if he hadn't been hospitalized with what turned out to be AIDS-related pneumonia.

"Nobody has any good reason to get tested by someone who's bound to report it until they're really in trouble--like me," the man said. "By the time I was tested I wasn't just HIV-positive. The disease had progressed to full-blown AIDS, because I was too scared to get tested. There was such a stigma."

But public health officials in Chicago and Springfield say there's nothing to worry about.

"We've been collecting names of AIDS patients for more than 20 years," said Tom Hughes, deputy director of the Office of Health Protection in the Illinois Department of Public Health. "We've never had a security breach of a patient's name in Illinois in all that time. I don't anticipate we'll have any problems handling HIV reporting."

In the city, providers report to the Chicago Department of Public Health, which sends the information to the Illinois Department of Public Health. The state strips out all identifying information before forwarding the data to the federal government.

Nanette Benbow, director of the Office of HIV/AIDS Surveillance in the Chicago Department of Public Health, said all HIV and AIDS case reports are kept in a locked file in a secured room, to which only two people have keys.

Some activists concede that state and city officials have an excellent track record.

"The Illinois and Chicago Departments of Public Health have a terrific reputation with regard to the confidentiality of the reporting system," said Ann Fisher, director of the AIDS Legal Council of Chicago. "Illinois has probably the best laws in the country protecting HIV confidentiality."

HIV and AIDS records are protected by law from subpoenas, and unauthorized disclosure is a crime, she said.

At a South Side clinic at 530 E. 31st St., officials said, only about 1 percent of clients ask for

anonymous HIV tests. But at the city's Lakeview facility, which serves a lot of homosexual men, about half the clients request anonymity.

Earlier this year, an official in Florida accidentally e-mailed the names of 6,500 HIV and AIDS patients to about 800 employees of the Palm Beach County Health Department. The mistake was caught quickly, and the names were never released outside the department. The very fact that it happened, however, makes some people nervous.

The AIDS Foundation, other community-based groups and health officials are taking pains to reassure the public that case reports will continue to be confidential and will be used only for monitoring the epidemic and targeting resources.

"We really do need to reach out and allay [people's] fears," said Benbow, of the Office of HIV/AIDS Surveillance. "It's really important they not stop testing, so they can get into care--and care is there."

Even after Illinois moves to name-based reporting, the state still could get short-changed financially. The CDC's latest HIV surveillance report did not count cases from states that started tracking by name only in the last few years, on grounds that the data were not yet complete.

The 14,000 HIV-positive Illinois residents in the state's database are all listed by code. Converting those cases into name-based files will require each patient to visit a physician, which could take years.

In November, AIDS groups sent a letter to Illinois' congressional delegation, pleading for Congress to allow states to phase in their name-based reporting programs without funding penalties.

U.S. Rep. Mark Kirk, a Republican from Highland Park, supports that idea, saying Congress must "make sure that no patients in Illinois lose funding because of the requirement to convert from code-based to name-based reimbursement."

Sen. Barack Obama of Chicago and Rep. Jan Schakowsky of Evanston, both Democrats, also vowed to ensure that Illinois isn't short-changed.

"We have a lot of HIV-positive folks [in Illinois], some low-income," Kirk said. "We now have the capability to save almost everyone from dying of AIDS, if we can make sure they keep up with treatment. So this is a life-or-death program."